Feasibility Study for Survey of Incomes and Assets of Adults with Social Care Needs

Workstream 4 (phase 2) report:
Findings from cognitive interviews with people with care needs and unpaid carers

Ipsos

Contents

This research was commissioned under the previous administration (11 May 2010 to 5 July 2024) and therefore does not reflect the policies of the current government. The views expressed are the authors' and do not necessarily reflect those of the government.

1 Executive summary

This summary outlines the key findings from 20 cognitive interviews with people with care needs, unpaid carers, and people with Power of Attorney for a family member. These aimed to test questions asking about the care needs, assets, and income of people with care needs, explore the acceptability of these questions, and participants' willingness and ability to answer them. These cognitive interviews constitute Phase 2 of Workstream 4 (WS4) of a larger project commissioned by the Department for Health and Social Care (DHSC) exploring the feasibility of collecting data on the care needs and finances of people with care needs to inform government policy.

1.1 Care needs

Questions asking about care needs, receipt of unpaid care and support and access to formal care services were considered acceptable to ask. As in the in-depth interviews conducted for WS4 (phase 1), both groups (people with care and support needs, and unpaid carers/people with Power of Attorney) were willing to answer questions on these topics. Sharing information about care needs felt safe, and participants were used to being asked for this sort of information in other contexts and could understand why DHSC might need this type of information. No one mentioned that questions on these topics were too intrusive, although it was acknowledged that they were personal.

There was some confusion about less familiar terms such as 'unpaid care and support' and 'formal care'. Participants were sometimes unsure whether they understood what they were being asked about.

The number of hours of unpaid care received appeared to be underestimated when the question was answered by people with care needs. Reasons included not counting tasks which they were aware of but did not actually see being done (e.g. shopping done for them in person or online, dealing with their finances), forgetting to include activities which were mentioned at other times during the interview, forgetting how frequently a friend or family member came over to visit and support them, or being reluctant to acknowledge the extent to which they relied on unpaid care and support. Conversely, the question was at times difficult for co-resident unpaid carers to answer or was answered but potentially over-estimated caring time. Providing care was an integral part of their life and where the person they cared for needed high levels of supervision they regarded all their waking hours as being hours they provided care. This is because even when they were not actively providing care, they were constantly keeping an eye on the person with care needs.

Other types of paid services were mentioned by participants which were not included in the list of formal care and support services provided at the question 'Do you use any of the following care and support services because of your physical health condition, disability, mental health condition or learning disability? These included supported living, personal alarm, and using a cleaner and/or a gardener because participants could no longer look after their home or garden as a result of their care needs.

There was some confusion about what 'formal care services' included when it was mentioned at the question 'how many hours of formal care and support do you receive each week because of your physical health condition or disability, mental health condition or learning disability', though the list of formal care services included at the previous question helped convey the meaning of the term.

1.2 Paying for care

There was widespread confusion about whether care was funded by the local authority or the NHS, especially among people with care needs. Although participants knew when a public sector organisation

was contributing financially to their care, they did not necessarily know which organisation this was. This issue adversely affected the routing throughout the rest of the survey. People with care needs who received help towards their care costs tended to think that the funding came from the NHS, but some also said that they were receiving direct payments and assumed these came from the NHS rather than their local authority.

Carers tended to know (and felt confident about their knowledge of) the amount paid towards care. The situation was more mixed among participants with care needs.

There was a lot of confusion about entering a monetary value and selecting the correct frequency of payments for care services, with participants not realising they could choose the frequency of payments until this was pointed out to them.

Participants sometimes also struggled to distinguish between household and individual finances. This issue was more prevalent in households with a co-resident carer.

The question asking about reasons for not receiving formal care was considered acceptable and important to ask (especially for carers), but codes 3, 4 and 5 which refer to formal care and local authority funded care were not well understood and therefore rarely selected.

1.3   Financial information

Overall, participants were cautious about providing information on their housing situation and finances. It was not clear to them why these were asked, how these related to care needs and how the information would be used.

There was reluctance when participants were invited to provide their postcode and permission for linking this to property value in the area. This was driven by a lack of clarity as to why this would be relevant information for DHSC, and concerns that the information could be used against them at a later stage (e.g. being forced to sell their home to pay for care).

There was a higher level of discomfort with questions related to income and assets, with participants suggesting they would answer 'Don't know' or 'Prefer not to say' at several questions in this section. They felt it was inappropriate to ask about sources of, and the value of, income and assets. On the rare occasions where participants were willing to answer these questions, they had low income and no or very few assets. As found in previous phases of this research, participants were most reluctant to provide information about savings and most willing to provide information on benefits. Going forward, it should be considered whether questions in this section of the survey should remain included.

Participants were more willing to answer questions related to perceptions of financial status, as they were seen as less intrusive and more about subjective feelings. However, questions were raised about how useful these would be since they are subjective and depend on a participant's point of comparison.

1.4   Willingness to take part in the survey

There was little or no change in participants' views about taking part in a survey on care needs, assets, and income once they had seen the questionnaire. Those who reported a change explained that they now felt less inclined to take part in the survey owing to its content. None of the participants said that they were more likely to participate in the survey if they received the questionnaire, having taken part in an interview.

In line with findings from the in- depth interviews earlier in Workstream 4, participants were more comfortable answering questions about care needs, than about finances. Those who were willing to answer questions on finances were participants with no or very few assets.

Questions on housing, linking postcode to property values in the local area, income, and assets generated worries and/or suspicion among many participants, who clearly wondered why such information was being collected. Worries related to scams, the information being used to reduce, remove, or make decisions about their entitlement to benefits or LA-funded care.

Despite providing an information sheet stating the aims and objectives of the survey, and explaining these at the start of the interview when seeking consent, there was still a fair amount of confusion about the aims of the survey among participants, with some believing the survey was a local authority assessment or similar, and that taking part and/or answering all the questions would help them access care and support, or was a requirement if they wanted to access care and support.

Views on where the survey invitation should come from (DHSC, local authority, or well-established research agency) were mixed. There was a preference for a self-completion mode, using a combination of paper and online approaches, although there was also a suggestion of a telephone survey. Paper questionnaires were thought to be convenient to those who wanted to discuss the questions with others or needed time to find the information required. Sending the survey invitation to unpaid carers or family members was thought to be acceptable when the person with care needs lacked capacity to take part.

2 Introduction

This report presents findings from workstream 4 (WS4) phase 2 of a project exploring the feasibility of collecting data about the income and assets of people with care and support needs. This section starts with an outline of the aims and objectives of the project as a whole, and describes the progress made so far. It then focuses on the objectives and methodology of the second phase of WS4, which involved cognitive interviews with carers and people with care needs.

2.1 Background and objectives of the Paying for Care Survey project

The project was commissioned by DHSC as there is currently a lack of robust data about the income and assets of the population using care services, as well as other information such as demographics and spending on care. The collection of these data can be complex and sensitive with important ethical implications. The overall project therefore looks to explore the different options for potential data collection and their benefits and drawbacks. This will help DHSC to have a better understanding of the future options for gathering these data available to them.

Continuing to develop the existing evidence base on the funding status, income, and assets (including property and/or savings) of people with care and support needs is essential to understand the needs of care users and how well they are supported by the systems and policies in place. However, there are challenges involved in collecting robust data on individuals' funding status, income, and assets, particularly from a population that includes vulnerable people. DHSC has therefore commissioned Ipsos and the Care Policy and Evaluation Centre (CPEC) at LSE to conduct a study to explore the feasibility and acceptability of conducting a survey to collect data on the characteristics of people with care needs, including financial data.

From the different options explored throughout this project, DHSC would like to understand how feasible it is to answer the following from any data:

- how the assets of people with care and support needs are impacted as they move through the care system

- how funding arrangements play out in the real world, and the issues faced by those in different funding scenarios

- what the demographic characteristics of people with care and support needs are

Improved data on the income, assets and wealth of people using care services will help DHSC to better understand the impacts of government policy and work to shape the charging reforms in the ASC sector. DHSC is interested in data which could be collected or analysed in advance of the implementation of the charging reforms, as well as future collection when the reforms are implemented. Existing survey data, administrative data and new surveys are all potential options to be considered.

2.2 The five work streams

The project was divided into work streams which were mostly conducted iteratively between December 2021 and October 2023. Earlier workstreams, which have been reported separately, involved conducting interviews with care providers, local authorities, and other key informants to assess the feasibility of collecting data on the income and assets of people with care and support needs:

Workstream 1: CPEC at LSE carried out a rapid evidence review of past studies on income and assets of people with care needs. They looked at existing large-scale national population datasets as well as previous bespoke surveys of people receiving care and support and their carers which collected data on income and savings. This provided DHSC with an overview of previous and current data collection.

Workstream 2: Ipsos explored the views of stakeholders with an interest in or understanding of the adult social care (ASC) sector. Participants were asked about the different ways that data on the income, assets, and wealth of people with care and support needs are currently recorded or collected and their thoughts on further potential data collection activities (such as a survey). A first Expert Reference Group (ERG) meeting was then held to discuss findings from WS1 and WS2 and inform the next phase.

Workstream 3: It consisted of secondary data analysis (phase 1) and an options appraisal (phase 2). For the secondary analysis CPEC investigated the response rates to questions about the financial circumstances of respondents in two major national longitudinal surveys, the English Longitudinal Study of Ageing (ELSA) and UK Household Longitudinal Study (UKHLS). The objective was to identify how well these questions in ELSA and UKHLS capture the financial information they are designed to capture. In the options appraisals, Ipsos looked at the different data collection options available. Three groups of options were considered, and their benefits and drawbacks identified. Each option was appraised on a range of topics including coverage of the target population, information that the option would provide and whether this would meet DHSC needs, impact on people with care needs, impact on carers and families, required involvement of organisations, technical and practical considerations and, data analysis and use. Findings from Workstreams 1 and 2 and from CPEC's secondary data analysis fed into the options' appraisal. This options' appraisal was conducted prior to the 2022 Autumn Statement announcement that the implementation of charging reform would be delayed.

Workstream 4 phase 1: This phase involved in-depth interviews which explored the views of people with care needs, unpaid carers, and people with Power of Attorney for the financial affairs of a family member with care needs, focusing on:

- their willingness to take part in a survey asking about their income and assets, or those of the family member they support;

- what level of detail they would be willing to provide when answering questions on care needs, assets, and income for themselves, or for the family member they support;

- how easy or difficult it would be to provide the required information about care needs, current care plan, income, and wealth;

- the role of family members in helping to provide the required information;

- possible concerns about how the data may be used; and

- how concerns could be reduced and alleviated and how people should be approached

Findings from these in-depth interviews fed into the design of questions to be cognitively tested in the next phase of WS4.

Workstream 4 phase 2 is the focus of this report. In this phase, Ipsos cognitively tested the survey questions drafted on the basis of the findings from WS4 phase 1. The cognitive interviews sought to understand:

- the extent to which unpaid carers and people with care needs understood the draft questions in the way they were intended;

- how easy or difficult it would be for carers and people with care needs to complete a survey using these questions; and

- the acceptability of the draft questions

A second ERG meeting was convened at the end of WS4 to discuss WS4 findings, the overall project findings and their implications.

Workstream 5: CPEC conducted further secondary analysis of ELSA data to explore how high level potential proxy measures of financial circumstance were related to more detailed financial evidence of the type needed for modelling the impact of charging reform.

2.3 REC approval

On 7 November 2022 Ipsos submitted an application for approval of this study with the Health Research Authority's (HRA) Research Ethics Committee (REC). As part of this process, the REC reviewed draft research materials for this phase of the study (in-depth interviews) and the following phase (cognitive testing). The materials reviewed were participant information sheets; consent forms; topic guides; support information; the project privacy notice; quotas and screening questions for recruitment. In addition, DHSC provided a letter of support as the research commissioner. The REC provided confirmation of its favourable ethical opinion for the research on 25 January 2023. Following the findings of phase 1 workstream 4, the questionnaire was developed and submitted to the REC as a substantial amendment. The REC provided a favourable opinion of the amendment on 23 May 2023.

2.4 Methodology

A total of 20 cognitive interviews were conducted for this second phase of WS4. Each interview lasted up to one hour and took place via Microsoft Teams or by telephone in June 2023. Interviews were carried out with people with care needs, unpaid carers, and people who have Power of Attorney for the financial affairs of a family member with care needs. Most interviews with people with care needs were conducted by telephone rather than MS Teams. The unpaid carers and people who have Power of Attorney who were interviewed in relation to their own role as an unpaid carer or someone with Power of Attorney were not related to the participants with care needs. During the cognitive interviewing phase none of the participants with care needs required a carer present to support them. The tables below outline the number of interviews completed across the two groups (people with care needs, and carers), as well as demographic information about the participants.

Table 2.1: Cognitive interviews

Participants' groups	Number of interviews
People with care and support needs	11
Unpaid carers and people who have Power of Attorney for the financial affairs of a family member with care needs	9
Total	20

Note that one unpaid carer had been recruited as someone with care needs but no longer had these at the time of interview, so instead participated as someone who had previously been a carer.

Table 2.2: Demographic information: people with care needs (x11)

Age	Social grade	Sex	Paid support
4x aged 18 to 64 4x aged 65 to 79 3x aged 80+	4x AB 3x C1C2 4x DE	6x females 5x males	2x people who receive paid support 2x people who receive paid and unpaid support 6x people who receive unpaid support 1x person who doesn't receive any support

Table 2.3: Demographic information: unpaid carers/people with Power of Attorney (x9)

Age	Social grade	Sex	Power of Attorney
6x people aged 36 to 64 1x people aged 65+ 2x aged 80+	2x AB 4x C1C2 3x DE	5x females 4x males	5x people exercising power of attorney for the financial affairs of a family member who lacks mental capacity 4x people who have (but are not yet exercising) power of attorney for the financial affairs of a family member who lacks mental capacity

Participants were sent the questionnaire for testing ahead of the interview. They were not expected to complete it ahead of the interview but this allowed them to have the questionnaire on paper in front of them while the interview was taking place – this was important as many interviews took place over the phone. Two different versions of the questionnaire were available: one for people with care needs and one for unpaid carers, with the wording for each question tweaked accordingly for each group.

To avoid participants having to provide responses on questions which they feel reluctant to answer, the interview focused on their views on the questions and how they would go about responding to them. They were not expected to provide an answer to the survey questions being tested.

2.5   Notes about the interpretation of findings

Cognitive interviews are designed to test survey questions and materials to ensure their relevance and clarity. Unlike quantitative surveys, this approach is not designed to provide statistically reliable data representative of the target population; rather, it is designed to be illustrative and exploratory, with findings presented thematically rather than quantified throughout this report.

Verbatim comments from the interviews have been included in this report. These should not be interpreted as defining the views of all participants but have been selected to provide insight into a particular issue or topic expressed at a particular point in time.

2.6   Acknowledgements

Ipsos would like to thank those who participated in the research and shared their views with us.

3 Care needs, unpaid support, and formal care

This section discusses participants' views about the draft questions regarding care needs, unpaid support, and formal care. It covers views on the acceptability and clarity of the question wording that used, and participants' willingness and ability to respond to the questions tested. It also looks at aspects of the draft questions that confused or concerned participants, and how these issues could be mitigated.

Key findings

As in the depth interviews conducted for WS4 (phase 1), both groups (people with care and support needs, and unpaid carers/people with Power of Attorney) were willing to answer questions about care needs. Sharing information about care needs felt safe, and participants were used to being asked for this sort of information in other contexts.

Participants tended to find the draft questions acceptable. No one mentioned these were too intrusive, although it was acknowledged that some were personal.

There was some confusion about less familiar terms such as 'unpaid care and support' and 'formal care'. Participants were sometimes unsure whether they understood what they were being asked about, although the specific examples helped.

Working out the number of hours of paid and unpaid care received was occasionally difficult and the responses provided by those with care and support needs may not be comparable with those provided by carers. Issues included uncertainty about what to include/exclude, forgetting to include some of types of care and support (particularly those receiving care), and not remembering how often a family member was visiting them to support them. For co-resident carers there was a tendency to respond about all the time they were with the person on hand to provide support.

3.1 Care need, unpaid support, and formal care survey questions

Question	Question wording	Instructions/routing
Care_needs_1	Do you have a physical health condition, disability, mental health condition or learning disability which means you have difficulty with any of the following day-to-day activities? Please select all that apply. 1. Getting in and out of bed 2. Washing your face and hands 3. Having a bath or a shower, including getting in and out of the bath or shower 4. Dressing or undressing, including putting on shoes and socks 5. Eating, including cutting up food 6. Taking the right amount medicine at the right times 7. Getting around indoors	ASK ALL

	8. Getting up and down stairs 9. Getting out of the house, for example to go to the doctors or visit a friend 10. Shopping for food including getting to the shops, choosing the items, carrying the items home and then unpacking and putting the items away 11. Doing routine housework or laundry 12. Doing paperwork or paying bills 13. None of these 14. Don't know [EXCLUSIVE] 15. Prefer not to say [EXCLUSIVE]	
Unpaid_Care_supp	Do you receive any unpaid care or support because of a physical health condition, disability, mental health condition or learning disability? This could be from a family member or friend. Please select one option only. 1. Yes, I do receive unpaid care and support 2. No, I do not receive unpaid care and support 3. Don't know 4. Prefer not to say	ASK IF Care_needs_1 =1-12 [not asked in carer version]
Unpaid_care_hours	How many hours of unpaid care or support do you receive each week from a family member or friend because of your physical health condition, disability, mental health condition or learning disability? Please only think about the hours they are helping you with care tasks and activities and not the time they spend in your home or when they are around to help in case you needed it. Please select one option only. 1. Less than 10 hours a week 2. 10-19 hours a week 3. 20-34 hours a week 4. 35-49 hours a week 5. 50 hours a week or more 6. Don't know 7. Prefer not to say	ASK IF Unpaid_Care_supp =1
Form_care_supp	Do you use any of the following care and support services because of your physical health condition, disability, mental health condition or learning disability? Please select all that apply. 1. Care home services 2. Home care services (a care worker coming into your home to provide care and support) 3. I employ a personal assistant to help with care and support 4. Voluntary or community support services (for example where someone from a charity spends time with you and helps you with day-to-day tasks) 5. Reablement services (support from a care worker to help you regain and retain skills so you can manage independently) 6. Visiting a day or drop in centre 7. Respite services (staying away from your home for a short period of time with another family, at a care homes service or other supported accommodation) 8. None of these 9. Don't know [EXCLUSIVE] 10. Prefer not to say [EXCLUSIVE]	ASK IF Care_needs_1 =1-12
Form_care_hours	Thinking about the [Form_care_supp_TEXTFILL] you use, how many hours of formal care and support do you receive each week because of your physical health	

| | condition or disability, mental health condition or learning disability? Please select one option only.

1. Less than 4 hours per week
2. 4-8 hours per week
3. 9-13 hours per week
4. 14-19 hours a week
5. 20-23 hours a week
6. 24-34 hours a week
7. 35-49 hours a week
8. 50 hours a week or more
9. Don't know
10. Prefer not to say | |

3.2   Feedback on questions in this section

Question Care_needs_1: Do you have a physical health condition, disability, mental health condition or learning disability which means you have difficulty with any of the following day-to-day activities?

Participants were generally happy to answer this question and did not consider it intrusive. Both groups said they were used to being asked about their care needs (or the needs of the person they care for) in other surveys for financial or needs assessments. One answer code, Code 3 (bath or shower), was considered slightly uncomfortable or intrusive, but on balance the code was considered relevant and appropriate in a question asking about care and support needs. A code for difficulty with using the toilet was deliberately not included in the question as findings from the in-depth interviews with people with care needs and unpaid carers (WS4 phase 1) showed this was very intrusive and potentially embarrassing for participants.

Having this broad question about care and support needs at the beginning of the survey appeared to be a useful way to prompt participants to think about the support they were receiving or providing. However, the list is fairly long, and occasionally participants skim-read the list rather than taking time to review each code. In order to increase the likelihood of participants reviewing the full list, and to avoid completion fatigue, we suggest changing the order of the codes so that those most likely to be chosen (e.g. codes 10, 11 and 12) appear at the top.

Additional day-to-day activities mentioned by participants included the following:

- personal grooming (for example: shaving; trimming fingernails and toenails)

- taking out the rubbish (as distinct from Code 11 – doing routine housework or laundry)

- gardening (as distinct from Code 11 – doing routine housework or laundry)

- keeping your home in a reasonable state of repair (as distinct from Code 11 – doing routine housework or laundry)

- additional considerations mentioned included the need to remind the person with care needs to do some day-to-day activities (for example: to eat, drink, wash or take medication), and/or the need for supervision when they engaged with some day-to-day activities, for safety reasons (e.g. to prevent choking during eating or taking medication), or because they had forgotten how to do the activity itself

These were considered distinct from needing help with the activity itself, which could still be done independently, once the person with care needs was reminded of it and/or supervised. A follow-up question could be added to cover these two points (e.g. Do you need to be reminded of or supported while doing any of your usual day-to-day activities?), or the phrasing of Care_needs_1 could be tweaked to include this.

Feedback on this question pointed to the importance of asking whether the person with care needs is co-resident with an unpaid carer. This could be asked in the demographics, and would give useful context for the analysis and interpretation of the findings.

Question Unpaid_Care_supp: Do you receive any unpaid care or support because of a physical health condition, disability, mental health condition or learning disability?

This question, asked to people with care needs, was also considered acceptable, and participants generally understood what was being asked of them. Occasionally, there was some confusion about the meaning of 'unpaid care and support', but the mention of 'support from family members and friends' helped to convey the intended meaning of the question. To ensure clarity, a sentence should be added before the two questions on unpaid care, explaining what it is.

Question Unpaid_care_hours: How many hours of unpaid care or support do you receive each week from a family member or friend because of your physical health condition, disability, mental health condition or learning disability?

Participants generally considered this question acceptable. However, there was some confusion across both participant groups about how to calculate their answer. For people with care needs, the distinction between 'paid care' and 'unpaid care' was not clear – likely because not everyone with care needs pays for their 'paid care'. As with the previous question, Unpaid_Care_supp, the mention of 'family or friends', contributed to the understanding of the question. When responding to this question, participants with care needs added up the time their unpaid carer spent with them during visits or on specific tasks, such as help with cooking, washing, or dressing. They tended to underestimate the number of hours of unpaid care and support they received. Issues included:

- not counting tasks which they were aware of but did not actually see being done (e.g. shopping done for them in person or online, dealing with their finances);

- forgetting to include activities which were mentioned at other times during the interview;

- forgetting how frequently a friend or family member came over to support them

It is also possible that some participants with care needs were reluctant to acknowledge (to themselves or others) how much help they received. All these factors led to underreporting of the number of hours of unpaid care these participants received.

Asking this question in a different way – for example, asking for an estimated number of hours per day, rather than per week – may help to make people with care needs feel more comfortable to answer. However, this is likely to work only for those who receive care and support on a regular basis, rather than ad hoc or irregular hours; it also would not address the issue of underreporting due to memory problems.

Unpaid carers also found this question difficult to answer. Those who did not live with the person they care for did not always know the number of hours of unpaid care provided by other family members. For those who were co-resident, providing care and support to a family member or friend tended to be considered an integral part of their life, so it could be challenging for them to calculate the number of

hours dedicated to these tasks. Answering the question required them to differentiate their role as a carer from their role as a family member, which they struggled to do. This question, as drafted, did not necessarily reflect that reality.

In addition, an important part of their role was to supervise the person they cared for, for example while eating, drinking, washing, and taking medication. Some co-residents unpaid carers explained they had to be there at all times as the person with care needs could not be left alone for safety reasons, but the sentence 'Please only think about the hours they are helping you with care tasks and activities and not the time they spend in your home or when they are around to help in case you needed it' made it unclear if the supervision time should be included or not. On balance, in most cases the supervision time was included when answering the question.

Overall, carers who were co-residents were likely to select Code 5 (50+ hours per week). Again this shows the importance of adding a question about co-residence.

Findings from CPEC's previous work[1] show that number of hours of unpaid care received or provided can vary with the way in which this information is requested, e.g. in a single question or in a set of questions about separate tasks because this affects what people include or exclude.

Question Form_care_supp: Do you use any of the following care and support services because of your physical health condition, disability, mental health condition or learning disability?

This question about formal care and support was generally considered acceptable, and participants were comfortable answering it. However, some of the answer codes were unclear to participants: in particular, 'personal assistant' was an unfamiliar term in this context for some people, and there was confusion about the difference between a 'personal assistant' and 'home care services.' Again, this could be addressed by providing definitions in a variety of formats, as described above.

Additional services which participants mentioned they were using as a result of their care needs were a cleaner, a gardener, taxis to go to e.g. medical appointments and a supported living service. These were important to participants who started using them following the onset of their care needs, and codes could be added to cover items such as these. If such codes are added, they should be worded in a way that makes it clear the question aims to capture services used because of care needs as opposed to choice, or followed by a question that aims to ascertain this distinction.

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[1] **Developing Improved Survey Questions on Older People's Receipt of, and Payment for, Formal and Informal Care**
King D.,1 Balarajan M.,4 Blake M., 4 Cheshire H.,4 Darton R.,2 Gray M.,4 Hancock R.,3 Henderson C.,1 Jones A.,3 Legard R., 4 Malley J.,1,2 Martin A.,3 Morciano M.,3 Mugford M.,3 Pickard L.,1 Shemilt I.,3 Snell T.,1 Wittenberg R.1
1. Personal Social Services Research Unit at the London School of Economics; 2. University of Kent;
3. University of East Anglia;
4. The National Centre for Social Research (NatCen)

Question Form_care_hours: how many hours of formal care and support do you receive each week because of your physical health condition or disability, mental health condition or learning disability?

Responses to this question were in line with participants' feedback about on the question regarding unpaid care hours participants felt comfortable answering, but found it relatively difficult. There were a few reasons for this:

- There was a significant lack of clarity around the term 'formal care'. When asked to describe 'formal care' in their own words, participants generally demonstrated the interpretation intended by the question, but participants were unsure whether they understood what they were being asked about. It was suggested to replace the term with 'paid care', though some participants got confused and mixed up the question with Unpaid_care_hours; and not everyone in receipt of formal care has to pay for it or contribute to its costs, so people whose care is fully funded by their local authority or the NHS may find the alternative term 'paid care' confusing.

- Participants were not sure whether tasks such as cleaning their home and gardening should be included in their calculations for this answer, which had an impact on their confidence in responding and to the totals reported.

- Some care services, which some participants used but were not included in Form_care_supp such as telephone reminders, alarm services if a person becomes unwell or falls, and supported living, do not lend themselves well to estimating a number of hours of use. Participants were not clear whether these should be included in their estimate. However, participants who used services such as home care found it relatively straightforward to calculate the number of hours for them (e.g. three times per day, five times per week).

- There was the option of a loop for this question so each service chosen at Form_care_supp was asked about separately, rather than asking about 'formal services' generally. Although this would make the questionnaire more repetitive for people using multiple services it would make it clearer what was being referred to here and avoid people having to add up hours from different services.

- The scale was not appropriate for services that may not be used weekly such as respite so was not asked for this type of service. However, participants were willing and able to report on the frequency of respite care and so a specific question about this could be added.

3.3   Differences in views between people with care needs and unpaid carers

Participants with care needs and unpaid carers were generally comfortable answering these questions, and understood why they were relevant to DHSC's research needs. There was more confusion about what to include when counting hours of paid or unpaid care, and more uncertainty about the meaning of some terms (e.g. unpaid care, formal care) or questions, among participants with care needs. This would impact on the accuracy and quality of the survey results for this group and the comparability of data between the two groups.

3.4   Recommended changes

Care_needs_1

- change the order of the list so that activities of daily living most likely to be mentioned (e.g. shopping, housework) are at the top

- consider adding codes for the following activities: personal grooming (for example: shaving; trimming fingernails and toenails); Taking out the rubbish; Gardening; Keeping your home in a reasonable state of repair

- consider adding the following sentence to Care_needs_1: 'Please include any activities you can do independently if you need to be reminded of it, or if you need someone with you to help keep you safe while doing it'

- include an additional question to both versions of the survey, to identify whether the carer is co-resident with the person with care needs, for those who have an unpaid carer

Unpaid_Care_supp

- add an introduction before the two questions on unpaid care, to explain what it is. For example: 'The next two questions are about unpaid care and support. This is usually provided by family members (e.g. a spouse, son and/or daughter) or friends, without them getting paid for this'

Unpaid_care_hours:

- provide example list of care and support activities to prompt participants, including tasks such as those that may more easily be overlooked by people with care needs, such as online grocery shopping and help with managing their finances

Form_care_supp

- explain what 'formal care' is

- provide definitions to explain what is meant by the terms 'personal assistant' and 'home care services'

- consider adding a question about equipment and technology used for support (e.g. personal alarms)

- consider adding the following codes:

    o 'a cleaner, because you are unable to clean your home independently'

    o 'a gardener, because you are unable to look after your garden independently'

    o 'taxis, because you are unable to walk, drive or use public transport'

    o 'supported living service'

Form_care_hours

- consider adding a sentence to explain what formal care is

- consider asking the question looped and referring to each service chosen at the previous question

- consider allowing people to choose the frequency before giving hours so it can be asked for respite care. Alternatively add an extra question for respite care using days per month or year rather than hours

4 Paying for current care

This section looks at participants' views on the questions asking how they currently pay for social care. It seeks to understand whether the draft questions are acceptable to this audience, as well as the extent to which participants are likely to be able to answer the questions independently.

Key findings

There was widespread confusion whether care was Local Authority or NHS-funded, especially among people with care needs. Although participants knew that when a public sector organisation was contributing financially to their care, they did not necessarily know which organisation this was. This issue adversely affected the routing throughout the rest of the survey.

People with care needs who received help toward their care costs tended to think that the funding came from the NHS, but also said that they were receiving direct payments (which is not a form of NHS funding).

Carers tended to know (and feel confident about their knowledge of) the amount paid towards care. The situation was more mixed among participants with care needs.

There was some confusion across the board about entering a monetary value and selecting the correct frequency of payments for care services.

Participants sometimes also struggled to distinguish between household and individual finances. This issue was more prevalent in households with a co-resident carer.

4.1 Paying for care survey questions

Question name	Question wording	Instructions/routing
Form_care_fund	Thinking about the [Form_care_supp_TEXTFILL] you use, how is this paid for? Please select all that apply. 1. I pay for all or some of the care and support service 2. My relative or friend pays for all or some of the care and support service 3. The local authority pays for all or some of the care and support service (include care paid for using a personal budget) 4. The NHS pays for all or some of the care and support service (this is known as Continuing Healthcare or CHC funding or NHS-funded Nursing Care) 5. A charity provides the care and support service free of charge 6. Someone pays for the care and support but I don't know who	ANSWER FOR EACH TYPE OF CARE USED ASK IF Form_care_supp=1-7.

	7. I do not know whether this service is paid for [EXCLUSIVE] 8. Prefer not to say [EXCLUSIVE]	
Form_care_pay_1	You mentioned that the local authority pays part of the cost for the [Form_care_supp_TEXTFILL] and you or someone else pays part of the cost. Which best describes how the cost is shared? Please select one option only. 1. The local authority only pays for part of the personal care from this service and I have to pay for the rest (because of the amount of income or savings I have) 2. The local authority pays for all the personal care from this service but I/my relative pay/pays a 'top up' for extra facilities or better quality care 3. The local authority pays for all the personal care from this service but I/my relative pay/pays for additional hours of care or extra care or services which are not in my care plan 4. The cost is shared in a different way (please specify) 5. Don't know 6. Prefer not to say	ASK IF Form_care_fund=1 and 3 or 2 and 3 (LA and self-funded).
Form_care_pay_2	You mentioned that the NHS pays for all or some of the cost for the [Form_care_supp_TEXTFILL]. Which best describes how the cost is shared? Please select one option only. 1. The NHS pay for all the costs of my personal care from this service 2. The NHS pays for part of the personal care from this service and I or my relative pay the rest 3. The local authority and NHS pay for all the personal care from this service 4. The cost is shared in a different way (please specify) 5. Don't know 6. Prefer not to say	ASK IF Q.Form_care_fund = 4
Form_care_pay_3	On average, how much do you pay toward the cost of the [Form_care_supp_TEXTFILL] you use? Please write a figure below and select how often you pay that amount. - WRITE FIGURE - Choose frequency (per week, per month, per year) - Don't know - Prefer not to say	ASK IF Form_care_fund=1 (self-funded)
Form_care_pay_4	[TEXTFILL IF Form_care_fund>1 ANSWER: Thinking of all the formal care and support services you use, / TEXTFILL IF Form_care_fund=1] how much do relatives or friends pay toward the cost of the care and support services you use? Please write a figure below and select how often you pay that amount. - WRITE FIGURE - Choose frequency (per week, per month, per year) - Don't know - Prefer not to say	ASK IF Form_care_fund=2 (relative/friend contributes)
Only_unpaid_care	You previously told us that you receive unpaid care and support from a family member or friend and that you do not use any formal care or support services. What are the reasons you do not use formal care and support services?	ASK IF Unpaid_Care_supp =1 AND Form_care_supp=

	Please select all that apply.	8,9,10 (none, DK, PNS)
	1. All my care needs are met by the help and support I receive from family members or friends	
	2. I prefer to receive care and support from family and friends	
	3. I do not know how to arrange formal care and support services	
	4. I do not qualify for local authority funded care and I cannot afford to pay for care and support services myself	
	5. I have applied for formal care and support services but nothing which meets my needs is available	
	6. Don't know [EXCLUSIVE]	
	7. Prefer not to say [EXCLUSIVE]	

4.2   Feedback on questions in this section

Question Form_care_fund: Thinking about the [Form_care_supp_TEXTFILL] you use, how is this paid for? Please select all that apply.

Feedback about the acceptability of this question about how care was funded was mixed. Among unpaid carers, those who do not manage financial matters tended to be willing to share information about how care is funded, though in most cases they would need to confer with the person who deals with finances to be sure of their answers. The person managing finances tended to be another relative or friend, but they were considered by the participant who did not manage financial matters to be less willing to provide the information as part of a survey.

Participants also found this question somewhat confusing and difficult to answer. People with care and support needs tended to know that their care is paid for, but it was not always clear to them how it was funded. This was particularly the case when they received funding from a public sector organisation: participants tended to say that 'the government pays', but did not know whether the funding came from their local authority or from the NHS, or assumed it came from the NHS but provided information that led the interviewer to think otherwise. This confusion adversely affected routing throughout the rest of the questions, so it is important that this be resolved in any future survey.

Question Form_care_pay_1: You mentioned that the local authority pays part of the cost for the formal care you receive and you or someone else pays part of the cost. Which best describes how the cost is shared? Please select one option only.

Question Form_care_pay_2: You mentioned that the NHS pays for all or some of the cost of the formal care you receive. Which best describes how the cost is shared? Please select one option only.

A minority of participants answered these questions (as they only applied to those who received local authority or NHS funding). These two questions were generally considered acceptable, but again participants found them confusing.

One element of confusion was due to these questions containing the term 'personal care'. Along with its meaning being unclear to participants, the term did not align with the wording used elsewhere in the survey. We suggest changing the question here to remove 'personal,' to match the wording used elsewhere.

The other confusing aspect about this question was in line with the feedback provided to the question Form_care_fund : participants, particularly people with care needs, were unclear about the difference between local authority and NHS funding for social care, and wrongly associated social care with the NHS.

Question Form_care_pay_3: On average, how much do you pay toward the cost of the formal care you use? Please write a figure below and select how often you pay that amount.

Question Form_care_pay_4: Thinking of all the formal care and support services you use how much do relatives or friends pay toward the cost of the care and support services you use? Please write a figure below and select how often you pay that amount.

These two questions about the amount paid for care (only asked to those who paid for formal care) were also generally considered acceptable, but, again, participants found them confusing or difficult to answer.

Among people with care needs, there were issues with recall about the amount paid for care. Although participants tended to know how they could find out the answers, some thought this could be challenging because it would involve having to find and review their records, or asking a family member or friend for help if they received help with manage their finances.

Unpaid carers tended to slip back and forth between thinking about (and reporting on) what they personally paid towards care, and, where relevant, the financial contributions of the person with care needs. Those who lived with the person they cared for and managed household finances found it hard to differentiate what they paid from what the person with care needs paid. Occasionally, it was difficult to remember or combine what everyone was paying when more than one family member was contributing to the care costs.

There was also some confusion across both groups about what value and frequency to indicate – occasionally the option to choose and select the frequency was missed. When the choice of frequency was pointed out, providing cost per week seemed to be the easiest for people to calculate. However, this option lent itself best to regularly scheduled care, rather than care that is more ad-hoc in nature (for example, respite).

Question Only_unpaid_care: What are the reasons you do not use formal care and support services?

This question about why formal care was not used was considered acceptable. Most responses focused on the codes 'All my care needs are met by the help and support I receive from family members or friends' (code 1) and 'I prefer to receive care and support from family and friends' (code 2). Some participants with care needs who selected code 1 did not acknowledge or realise that they needed help, or that the amount of unpaid help and support they needed would justify them or their family considering formal care services or asking for a local authority assessment. They sometimes appeared to underestimate the amount of care and support their unpaid carers provided them e.g. when working out number of hours of unpaid care received, they did not include activities or support mentioned at other times during the interview. It is important to note that this issue was raised by some participants with care needs, as well as by carers.

Code 2 was selected by carers only, it was not clear whether it reflected their own views, the views of the person with care needs, or any assumption they made about the preference of the person with care needs.

The responses to the following codes 'I do not know how to arrange formal care and support services' (code 3), 'I do not qualify for local authority funded care and I cannot afford to pay for care and support services myself' (code 4) and 'I have applied for formal care and support services but nothing which meets my needs is available' (code 5) were affected by people's perceptions of the situations, and their understanding of the codes. As with Form_care_hours, participants were unclear about the meaning of 'formal care' and may benefit from being offered a definition. These affected their understanding of codes 3 and 5 (these codes were very rarely selected).

As previously mentioned, understanding of how care and support is funded was limited and this affected understanding of code 4 about 'qualifying for local-authority funded care' – it is possible that people did not select it because they did not know whether they qualified or not, rather than because it did not apply to them. Other comments related to the term 'family and friends': one participant wanted a distinct code about preferring to receive care and support from their spouse as opposed to other family members, and another one that the unpaid care and support was provided exclusively by family members rather than friends. Multiple responses might apply to people but not be the reason they do not use care and support services.

4.3   Differences in feedback between people with care needs and unpaid carers

People with care needs were less likely than unpaid carers to have detailed knowledge about how their care is funded. This was especially the case in relation to knowledge about funding from a local authority or the NHS. People with care needs also tended to struggle with recall about the financial aspects of their care, and were likely to need assistance from a friend or family member to answer these questions.

Unpaid carers managing the finances of a person with care needs were described by other unpaid carers as being perhaps more reluctant to give away information about the cost of care or financial information more generally, compared with unpaid carers who were more focused on day-to-day caring responsibilities and less aware of the care recipient's financial position.

4.4   Recommended changes

Form_care_fund

- provide guidance on how to find out where the funding is coming from (local authority vs NHS)

Form_care_pay_1 and Form_care_pay_2

- remove references to 'personal' in 'personal care' within answer codes to match the wording used elsewhere in the survey

Form_care_pay_3 and Form_care_pay_4

- adapt questions to situations where services are paid from a joint account (typically held by a care recipient and their spouse)

- tweak questions to make it clearer the answer should include the care costs covered by all family members and friends, in cases where more than one person contributes

- retain variety of choice of frequency in answer codes

Only_unpaid_care

- consider replacing this question by a number of simpler questions (e.g. on eligibility for local authority funded care), and some attitudinal statements (e.g. on preference for unpaid care, knowing how to arrange formal care if needed it, etc).

- consider an alternative term for 'formal care,' or provide a definition in a mode-appropriate format

5 Financial information: housing value, income, and assets

This section describes participant views on the questions related to housing value, income and assets, and perceptions of financial status. This includes the acceptability of these questions, participant understanding of the question wording and answer codes, and recommendations for how questions could be improved.

Key findings

Overall, participants were cautious about providing information on their housing situation and finances, as it was not clear how these related to care needs and how the information would be used.

There was reluctance when participants were invited to provide their postcode and permission for linking this to property value in the area. This was driven by a lack of clarity as to why this would be relevant information for DHSC, and concerns that the information could be used against them at a later stage (e.g. being forced to sell their home to pay for care).

Similarly, some participants were uncomfortable providing their postcode so it could be linked to ONS data on property values. Participants felt it was unclear why this would be relevant information for DHSC.

Participants suggested they would be reassured if the survey included an explanation around why this information would be needed and how it would be used.

There was a higher level of discomfort with questions related to income and assets, with participants suggesting they would answer 'Don't know' or 'Prefer not to say' at several questions in this section. They felt it was inappropriate to ask about sources of, and the value of, income and assets. On the rare occasions where participants were willing to answer these questions, they had low income and no or very little assets. It should be considered whether questions in this section of the survey should be included going forwards.

Participants were more willing to answer questions related to perceptions of financial status, as they were seen as less intrusive and more about subjective feelings.

5.1 Housing value survey questions

Question name	Question wording	Instructions/routing
Home_own	Do you own or rent the property you live in? Please select one option only. 1. I am buying it with a mortgage on my own 2. I am buying it with a mortgage with a spouse / partner / someone else 3. I own it outright on my own 4. I own it outright with a spouse / partner / someone else 5. I rent it from a local authority 6. I rent it from a Housing Association / Trust 7. I rent in from a private landlord 8. Other – PLEASE SPECIFY 9. Don't know 10. Prefer not to say	ASK ALL
Home_postcode	Could please tell us the postcode for where you live? This information will be used by Ipsos only and will not be shared with any other organisation. - ENTER POSTCODE - Don't know - Prefer not to say	ASK ALL
Home_postcode_link	We would like to ask for your consent to link the postcode you have provided in this survey with data from the Office of National Statistics (ONS) about property values and rents in your area. To do this we need your consent, no personally identifiable information will be shared with ONS and this information will only be used for analysis purposes. Do you consent to your postcode data being linked with information on property values in your area from the ONS? 1. Yes 2. No	ASK ALL

Question Home_own: Do you own or rent the property you live in?

Participants found the question wording and answer codes clear and easy to understand. However, they felt the answer codes did not reflect the possibility that people with care needs may live with family members or friends. Although participants suggested that a respondent could select 'Other' at this question, they felt this answer would be common and would require an additional answer code.

Participants were also asked how they would feel about answering this question in a survey. Overall, participant views on the question fell into three main categories:

- **Confused:** Participants were surprised and unsure why a question on housing had been included in the survey. They felt the questionnaire was mainly about care needs and it was not clear why the question was included. A few participants said they would answer 'Don't know' as they were unclear why DHSC would need this information.

- **Uncomfortable:** These participants were uncomfortable being asked this question as they did not feel it was appropriate for DHSC to ask about home ownership. Participants said they would respond to this question by selecting 'Don't know' or 'Prefer not to say'.

- **Comfortable:** These participants were clear on the purpose of the survey and why this question was included, they did not feel it was inappropriate and said they would provide an answer.

Question Home_postcode: Could please tell us the postcode for where you live?

Question Home_postcode_link: Do you consent to your postcode data being linked with information on property values in your area from the ONS?

Participants were asked to provide their postcode, followed by a second question (Home_postcode_link) which explained that Ipsos would like their consent to link their postcode with data from the Office of National Statistics (ONS) about property values and rents in their area.

In terms of comprehension and understanding, there were no issues at these questions. However, as for Home_own, participants were initially unclear why they were being asked to provide their postcode. This indicates that it would be helpful to swap the order of the questions, with an explanation of how the postcode data would be used given to participants before asking them to provide it.

Once participants had read both questions, there was still some caution about providing their postcode and consenting for this to be linked to ONS data. Participants who were concerned, often commented that they felt this information was private and were worried about being identified. Linked to this, there were worries about how this information could be used. For example, one participant suggested they would be worried about their benefits being limited, if it was determined that their property was of a particular value. Another participant reflected that the question was a 'roundabout way' of asking how much their property was worth and felt this approach was not transparent. Finally, a carer explained that the person she cared for was adamant that he did not want to sell his home to pay for care: she was reluctant to agree to the data linking for fear that the information could be used against them.

Other participants were more comfortable with these questions and could see that it may be useful for looking at geographical differences across England. They felt that a postcode was broad enough to ensure they would remain anonymous. Participants who were comfortable providing answers at these questions were also considering how this could help improve social care policy in the future.

5.2   Income and assets survey questions

Question name	Question wording	Instructions/routing
Source_income	Do you receive any of the following? Please think about income you receive yourself in your own name or your share of a joint income. **Please select all that apply.** 1. Income from paid employment 2. Income from self-employment 3. Government benefit payments (such as Universal Credit or Statutory sick pay) 4. Direct payments for paying for care and support 5. Income from the state pension 6. Income from a private pension 7. Income from savings 8. Income from rental property 9. Income from investments or other assets (e.g., stocks, shares, bonds) 10. Other – PLEASE WRITE IN 11. Don't know 12. Prefer not to say	
Bene_income	Which of the following benefits do you receive? Please think about benefits you receive yourself, in your name. Please select all that apply. 1. Employment and support allowance (ESA) 2. Universal credit 3. Statutory sick pay (SSP) 4. Job seekers allowance (JSA) 5. Pension credit 6. Personal Independence Payment (PIP) 7. Attendance allowance 8. Disability living allowance (DLA) for children 9. Industrial Injuries disablement benefit 10. Reduce earnings allowance 11. Carers allowance 12. Other 13. Don't know 14. Prefer not to say	

Fin_Income	Thinking about your total annual income from the sources you previously selected such as [TEXTFILL], which of the following best describes the total value of your individual annual income? 1. £1 to £9, 999 2. £10, 000 to £19,999 3. £20, 000 to £29,999 4. £30,000 to £39,999 5. £40,000 to £49,999 6. £50, 000 to £74, 999 7. £75, 000 to £99, 999 8. £100, 000 or more 9. Don't know 10. Prefer not to say	

Nonchargeable_Income	You have said that your total annual income is around [TEXTFILL from Q. Fin_Income]
	
	How much of this income, if any, would you estimate is from the following sources combined:
	
	- **Income from paid employment or self-employment (not including any pension income)**
	- **Any of the following benefits:**
	  a) **the mobility component of Disability Living Allowance**
	  b) **the mobility component of Personal Independence Payments**
	- **Direct payments from the local authority to pay for care and support**
	
	1. £1 to £9, 999
	2. £10, 000 to £19,999
	3. £20, 000 to £29,999
	4. £30,000 to £39,999
	5. £40,000 to £49,999
	6. £50, 000 to £74, 999
	7. £75, 000 to £99, 999
	8. £100, 000 or more
	9. Don't know [EXCLUSIVE]
	10. Prefer not to say [EXCLUSIVE]	

Fin_assets	Which of the following best describes your estimated total financial assets (excluding the value of the home you live in)?	

	Please include savings accounts, stocks, shares or investments and any property which is not your main residence. If you have joint assets, please give the estimated value of your share of them.Please select one option only. 1. Under £10k 2. £10k to £19k 3. £20k to £29k 4. £30k to £39k 5. £40k to £49k 6. £50k to £59k 7. £60k to £69k 8. £70k to £79k 9. £80k to £89k 10. £90k to £99k 11. 100-149k 12. 150-199k 13. 200k+ 14. Don't know 15. Prefer not to say	

Question Source_income: Do you receive any of the following? Please think about income you receive yourself in your own name or your share of a joint income.

Overall, there was good comprehension at this question. Participants felt the answer codes were relevant and covered the different answers they could provide. As with the questions on housing, there were participants who expressed caution about providing an answer to this question and would like to receive more information about how this data would be used and inform the work of DHSC.

Participants who were comfortable answering this question, suggested that not all of the answer codes were relevant, with some sources of income more common than others. For example, there was a perception that people with care needs would be more likely to receive government benefits or income from a state or private pension rather than paid employment. This suggests it would be useful to re-order the answer codes based on the most relevant answers.

In-work benefits were considered less relevant than disability benefits for participants. Participants mentioned Personal Independence Payment (PIP) as a relevant example of a benefit.

Question Bene_income: Which of the following benefits do you receive? Please think about benefits you receive yourself, in your name.

Participants reported that the question wording about income from benefits was clear, and they were comfortable answering the question. This was mainly due to the perception that the 'government' already knew which benefits participants would be receiving. Therefore, it was not seen as a confidential or sensitive topic to ask about. However, for a similar reason, a minority of participants felt this question was not necessary as the 'government' already had this information and for this reason they would respond 'Don't know' or 'Prefer not to say'.

Although there was good comprehension at this question, the cognitive testing highlighted a routing consideration. At question Source_income those in receipt of benefits did not always select that they received government benefit payments (such as Universal Credit or Statutory sick pay), so should not have answered Bene_income. However, most participants read through to this question, and it was only at this point that they mentioned they were receiving government benefits such as attendance allowance or pension credit (as they recognised them on the list). The examples of benefits currently mentioned at Source_income (Universal Credit, Statutory Sick Pay) should be replaced by some that are most relevant to the survey audience (e.g. pension credit, attendance allowance, PIP). In addition, the question Bene_income could be asked to all participants regardless of their response to Source_income.

Question Fin_income: Thinking about your total annual income from the sources you previously selected such as [TEXTFILL], which of the following best describes the total value of your individual annual income? The wording of this question about income was well understood; however, most participants were uncomfortable providing an answer to this question and said they would select 'Don't know or 'Prefer not to say'. There were several reasons why participants were less willing to provide an answer. This includes:

- carers were not sure the person they cared for would be happy for them to provide this information on their behalf. The person with care needs was often portrayed by participants as being more reluctant to provide this information and concerned about privacy

- participants with care needs also reflected on their worries that the information could be used against them in some way, for example, by reducing their access to care services or benefits. They were also worried that this information may fall into the hands of scammers, and they could be targeted or defrauded

- participants who had more financial assets or different sources of income were more likely to say they did not feel comfortable answering this question, as this was a sensitive and private topic

Although participants were reluctant to answer this question, they were asked how they would go about calculating their answer and how easy or difficult it would be. Most participants calculated their income based on their private and/or state pension plus any other benefits they received. However, it was quite difficult to do this calculation quickly and participants suggested they may need more time to work this out. Carers suggested they would need time to look at financial paperwork and consult with family members who were more involved in the financial management of their family member's income and assets.

Participants also suggested splitting code 2 (£10, 000 to £19,999), as an annual income of £10,000 was very different from an annual income of £19,999. This would also apply to code 1 (under £10,000).

Question Nonchargeable_Income: You have said that your total annual income is around [TEXTFILL from Q. Fin_Income] How much of this income, if any, would you estimate is from the following sources combined: Income from paid employment or self-employment (not including any pension income), any of the following benefits: a) the mobility component of Disability Living Allowance b) the mobility component of Personal Independence Payments, Direct payments from the local authority to pay for care and support.

Participants found this question about 'non-chargeable' income from employment and self-employment, mobility component of PIP or DLA and direct payments confusing and difficult to answer. Participants said this was challenging to calculate, as the question asked about several different sources of income and how this related to their overall income. It should also be noted that at earlier questions there was

confusion about direct payments and what is meant by them. This echoes CPEC's analysis of data on direct payments from other surveys, which show the confusion between local authority direct payments for care and receipt of DWP benefits.

Calculating their income from employment, benefits and direct payments from local authorities was too much of a cognitive burden for participants who received these sources of income. It suggests this question should be split in three, for example a question on income from paid employment and self-employment and then a second question about income from benefits, and a final question about direct payments from local authorities.

While splitting this question into two would reduce the cognitive burden on participants, it is important to note that participants also felt this level of detail about their income was not appropriate. As found for Fin_Income, participants would be more likely to select the code 'Don't know' or 'Prefer not to say'.

The one element which was more straightforward and acceptable was the mobility component of PIP and DLA. These are standard amounts and so it is not necessary to ask the amounts: instead this could be calculated if people are asked for the level they are on.

Question Fin_assets: Which of the following best describes your estimated total financial assets (excluding the value of the home you live in)?

Participants found the question wording and answer codes in this question about financial assets clear and easy to understand. However, the paragraph explaining the inclusion of saving accounts, stocks, shares and investments and any property was not seen as relevant, as most of the participants interviewed did not have these assets.

To an even greater extent than the other questions in this section of the survey, participants were unwilling to provide an answer to this question as they were unsure how the information would be used and why DHSC needed to know this. They were worried about it potentially impacting their current or future entitlement to care and support. These participants said they would be most likely to answer 'Don't know' or 'Prefer not to say' at this question. This is not information they would generally be willing to share with anyone.

Those who said they would be willing to answer the question suggested that the first code is split into two (Under £5k, £5k to 10k), as they felt having less than £5K in financial assets was quite different from e.g., having £9k.

Generally, the participants who tended to say they would be comfortable answering this question described having no or very few assets, so they were less worried about the impact providing an answer could have on them. This suggests there is a risk that the data collected from this question could be biased towards those with a lower level of assets, and to an extent that could not be corrected by weighting. As with the other questions in the survey which ask about level of income and assets, the inclusion of this question should be considered, as it is likely people will not provide an answer or the answer received will underestimate the level of assets they hold and will be biased towards those with low levels of assets.

5.3   Perceptions of financial status survey questions

Question name	Question wording	Instructions/routing
Con_FinSit	Rate your current financial situation, using a scale from 1 to 7, where 7 means your personal financial situation is very strong today and 1 means it is very weak. Please select one option only 1. 1 – Very weak 2. 2 3. 3 4. 4 5. 5 6. 6 7. 7 – Very strong 8. Don't know 9. Prefer not to say	
Con_EXRELA	Looking at this card, please say how often you find you have too little money to spend on what you feel [your / you and your household's] needs are? Please select one option only. 1. Never 2. Rarely 3. Sometimes 4. Often 5. Most of the time 6. Don't know 7. Prefer not to say	
Con_IAFCON	Which of these phrases best describes how you and your household are getting along financially these days? Please select one option only. 1. Manage very well 2. Manage quite well 3. Get by alright 4. Don't manage very well 5. Have some financial difficulties 6. Have severe financial difficulties 7. Don't know 8. Prefer not to say	

| Con_EXRELE | Does having too little money stop you from doing any of the following things?

Please select all that apply.

1.   Buy your first choices of food items
2.   Have family and friends round for a drink or meal
3.   Have an outfit to wear for social or family occasions
4.   Keep your home in a reasonable state of decoration
5.   Replace or repair broken electrical goods
6.   Pay for fares or other transport costs to get to and from places you want to go
7.   Buy presents for friends or family once a year
8.   Take the sorts of holidays you want
9.   Treat yourself from time to time
10.   None of these
11.   Don't know | |

Question Con_FinSit: Rate your current financial situation, using a scale from 1 to 7, where 7 means your personal financial situation is very strong today and 1 means it is very weak.

This question was well understood by participants and the process of rating their current financial situation on a scale of 1-7 was intuitive for most. The majority of participants selected 4 or 5, as they felt they had enough money to pay for the things they needed, as long as they managed their finances sensibly but did not have a high amount of savings or spare money.

Participants reflected that this question could be quite subjective and for some this made it more difficult to provide an answer as it was unclear if they were providing a sensible answer compared to others. Participants on occasion compared their current financial situation with times in the past, rather than comparing themselves with others. Participants also mentioned the rating people provide may change depending on the time of year they are asked. For example, a participant commented that if she had been asked this question during the winter, she would have given a lower rating as they were struggling to pay higher energy bills.

Generally, participants were more willing to answer this question and the others related to financial status compared with the questions included in the section on Income and Assets, as it was seen as less intrusive and more about their own subjective feelings. This suggests that this question and the others included in this section would be more likely to provide an indication of participants' financial circumstances, though it would be subjective.

Question Con_EXRELA: Looking at this card, please say how often you find you have too little money to spend on what you feel [your / you and your household's] needs are?

There were good levels of comprehension at this question, although a few participants found the wording confusing, particularly the term 'what you feel your needs are'. Participants were able to provide an

answer and explain their reasoning for this. As for the previous question, the answer to this question could vary depending on when it is asked. For example, one participant said they generally managed well as long as they could make sure they would not need to pay for chiropody and the gardener in the same week, and as this would cause temporary financial difficulties.

Question Con_IAFCON: Which of these phrases best describes how you and your household are getting along financially these days? The question wording and answer codes were well understood by participants, and they were able to select an answer they felt was appropriate. However, the answer selected could be subjective. For example, several participants mentioned that they received benefits and were living in housing which was provided by the local authority, but would choose 'manage quite well'.

When asked how participants determined their answer, they would often compare their current situation to how they managed financially in the past or to other people. These differing perspectives mean that people in similar financial situations could select different answers at this question. It is also possible that answers provided in the cognitive interview may differ if the question was asked in a self-completion survey, as participants may not want to admit their financial difficulties in an interview.

The term managing very well could be confusing where people with care and support needs cannot manage their finances themselves.

Question Con_EXRELE: Does having too little money stop you from doing any of the following things?

Participants found the question wording and answer codes clear and easy to understand. However, it could be considered insensitive to include some of these activities in the question, as participants may not be able to do things like go on holiday or keep their home in a reasonable state of decoration because of a disability, physical or mental health condition, rather than financial issues. Carers supporting people with substantial care needs felt the list of activities was not relevant to the person they supported.

5.4   Recommended changes across the financial status section

Home_own

Add an answer code to reflect the scenario where a person with care needs is living with family or friends.

Add an introductory paragraph at the start of the section which explains the purpose and relevance of the housing questions.

Home_postcode and Home_postcode_link

Swap the ordering of Home_postcode and Home_postcode_link so it's clear to participants how their postcode data will be used before being asked to provide it.

Do not ask about housing value if the person is living in rented property or the home of a family member as the value is not an asset belonging to them

Add an explanation outlining why DHSC is interested in housing value, how this relates to the purpose of the survey and how the information will be used e.g., there will be no change in benefits and entitlement to local-authority funded care, no identifiable data or postcodes will be shared with DHSC or local authorities.

Source_income

Re-order answer codes based on the sources of income which are most common for people with care needs.

Update the examples of benefit payments to include disability and pension related benefits.

Add an explanation outlining how information from this question will be used and reassuring participants that the survey is anonymous.

Bene_income

Update routing so the question is asked of all participants not only those who select code 3 (receive government benefit payments such as Universal Credit or Statutory sick pay)

 at Source_income.

Update the example benefits listed at Code 3 so they are more relevant for people with care and support needs.

Reorder the list of answer codes so that benefits which are more relevant for people with care and support needs and older people are nearer the top of the list.

Fin_Income

Consider whether this question should be included in the survey, as it is likely to receive a high proportion of 'Don't know' or 'Prefer not to say' responses with those providing substantive responses not necessarily being representative of the eligible population.

If the question is included in the survey, specify whether it is net income or gross income (net is easier to provide) and make it very clear whether it is individual or household income (question tested was individual but household may be more relevant).

If the question is included in the survey, split the answer codes 1 (£1 to £9, 999) and 2 (£10,000 to £19,999) so they have narrower bands (though for some people this may make the question more sensitive as it will be more specific).

It will also be important to select a survey format or mode that will allow people to return to this question so they can calculate their answer separately once they have checked financial paperwork and/or consulted with other family members.

Nonchargeable_Income

Consider whether this question should be included in the survey as participants are more likely to answer the question 'Don't know' or 'Prefer not to say'.

If the question is included in the survey, split it into three separate questions, one asking about income from paid employment and self-employment, which level of the mobility component of PIP or DLA they are on, and amounts from direct payments (with sufficient detail that people only include the direct payments intended at this question).

Add the abbreviation of personal independence payments (PIP) and disability living allowance (DLA) in brackets after mentioning them in full in the question wording as the acronyms are more recognisable to participants.

Fin_assets

Consider whether this question should be included in the survey as respondents are more likely to answer the question 'Don't know' or 'Prefer not to say' and the substantive responses are likely to be biased towards those with lower levels of assets.

Con_EXRELE

Consider removing Con_EXRELE because of the emotional impact it could have on survey participants, and because the list of activities is not appropriate to people with substantial care needs.

Include question on perceptions of financial status earlier in the questionnaire as these were more acceptable to participants than detailed questions on housing, level of income and assets.

6 Views on taking part in a future survey

Toward the end of their interview, participants were invited to share their feelings about taking part in the survey asking about care needs, income and assets, now that they had seen the questionnaire, and whether their views had changed as a result of the discussion. Participants were also asked how they would most like to be approached to take part in a survey about their care needs, assets, and income, and who should be invited to complete the survey in the situation where a person with care needs is unable to take part. This section outlines their views on these issues and assesses options for the administration of the survey.

Key findings

There was little or no change in participants' views and feelings about a survey on care needs, assets and income once they had seen the questionnaire. Those who reported a change explained that they now felt less inclined to take part in the survey due to its content. None of the participants said that they were more likely to participate or provide information on these subjects, having taken part in an interview.

In line with findings from the depth interviews earlier in WS4, participants were more comfortable answering questions about care needs, than about finances. Those who were willing to answer questions on finances were participants with no or very few assets.

Questions in housing, data linking income and assets generated worries and/or suspicion among many participants, who clearly wondered why such information was being collected. Worries related to scams, the information being used to reduce, remove or make decisions about their entitlement to benefits or LA-funded care.

Despite providing an information sheet stating the aims and objectives of the survey, and explaining these at the start of the interview when seeking consent, there was still some confusion about the aims of the survey among participants, with some believing the survey was an local authority assessment or similar, and that taking part and/or answering all the questions was necessary to help them access care and support.

Views on where the survey should come from (DHSC, Local Authority, well-established research agency) were mixed. There was a preference for a self-completion mode, using a combination of paper and online approaches, though telephone was also mentioned. Sending the survey invitation to unpaid carers or family members was thought to be acceptable when the person with care needs lacked capacity to take part.

6.1 Willingness to take part in a survey

Having seen the questionnaire, all the interview participants reported either that their views had not changed, or that they now felt less inclined (or not inclined at all) to take part in the survey, because of

some of the questions it contained. None of the participants said that they were more likely to participate or provide information on these subjects, having taken part in the interview.

Despite having read the participant information sheet, and having had the purpose of the cognitive interview explained to them, sometimes more than once, participants' understanding of the purpose of the survey was limited and there was a lot of confusion around its aims and objectives.

> **"They are not helping people on benefits who have care and support needs. It is not about health; it has gone off the road."** – Person with care needs

> **"I can't see the point. With so little time … there is no benefit at the end of it. The person with care needs will not benefit from them filling out this form, so they won't be bothered."** – Unpaid carer

When a participant who said she would be willing to take part in the survey was asked about her motivations, it became clear that she thought taking part would allow the person she cared for to access care and support (or more of it): she wrongly understood it to be a social care assessment. Once the confusion was cleared up, she did not see the point of it anymore and said she would not take part if she received the questionnaire. This clearly indicates that the purpose of the survey needs to be clarified in the introduction and invitation letter, to avoid raising people's expectations about a possible outcome if they decide to take part.

> **"Could this form be there to help people in the near future, try and sort out some extra care?"** – Unpaid carer

An additional consideration was the potential for the survey to generate suspicion about whether the survey is genuine and worries about what might happen as a result. These were more common among people with care needs. Worries would include being scammed or defrauded after having given away financial information, having benefits reduced or removed, being refused LA-funded care if and when they approached their local authority for an assessment, having their LA-funded care package reduced, and being required to sell their home to pay for care. Paying for care was a sensitive and emotional topic for some participants. Interviewers were able to manage these sensitivities and worries during the interview, but this would not be possible in a self-completion survey. Furthermore, in these interviews participants did not need to provide an answer to the questions, but in a survey if they chose not to answer by selecting 'prefer not to say' this would limit the value of them taking part and could lead to biases in the data obtained.

Participants tended to feel more comfortable answering questions about care needs, than about finances. Although some participants understood the reasoning for DHSC wanting to collect information about the income and assets of people with care needs, there was a general reluctance to provide potentially identifiable information such as a postcode. This was due in part to feeling that financial matters are private, and 'nobody else's business.' Participants were also uncomfortable about the possibility of data linkage and concerned about benefits being reconsidered in light of new or different information. As a result, there was a theme of choosing 'Prefer not to say' in response to many of these questions.

> **"People might be worried that if they declare they own the house they live in, would they not be able to get care, or would they be excluded, if you tell the government this information… The assets and income part I wouldn't like, it's a big no-no. It's too personal. The rest of the questionnaire is fine."** – Person with care needs (who is also an unpaid carer)

> **"It isn't relevant outside of a financial assessment. I don't understand why the financial information is being requested."** – Unpaid carer

The minority of participants who said they would be willing to take part in a survey tended to be those who had few (or no) assets to report, and took the view that they had 'nothing to hide'. Older people were likely to be more wary about sharing personal information, citing privacy concerns and the proliferation of scams targeting vulnerable populations.

6.2   Who the survey should come from

In terms of who the survey should come from (DHSC, local authority, a well-established research agency), views were mixed. A key factor underlying people's views about this was the perception that if a survey comes from DHSC or their local authority, it is more likely to be genuine and its results are more likely to have an impact because DHSC and local authorities can make policy changes at national or local level. However, there was also some suspicion, and a fear that entitlement to benefits and to LA-funded care could be affected if DHSC or the local authority have access to their identifiable financial data – it was assumed that they would have access if the survey were to come from them directly.

> **"I would want to be contacted directly by DHSC or Ipsos so you know it's a real thing."** – Unpaid carer

6.3   Views on survey mode

Having seen the questionnaire, people with care needs tended to say they would prefer a paper self-completion mode, because it would give them the time to read and reflect on the information at their own pace, and discuss it with family members if necessary. However, as mentioned above, older people in particular had concerns about scams, and indicated they may not trust an invitation for postal survey. Preference for an interviewer-administered modes (telephone or face-to-face) was limited and driven by accessibility considerations.

In contrast, unpaid carers tended to favour an online mode of completion. This may be linked with the younger age range of this group. Carers also mentioned that the people they cared for were likely to feel uncomfortable or unable to complete a survey online, or that they would need a lot of help to do so.

6.4   Who should complete the survey

Views on who be invited to complete the survey were mixed. Where possible, it was felt that the invitation should be address to the person with care needs, as long as they had mental capacity, so they could try to complete it themselves, with or without the support of a family member or friend. Inviting a family member or friend to complete the survey on behalf of a person with care who lacked the capacity to do so was considered acceptable, both among participants with care needs and unpaid carers. Occasionally, unpaid carers mentioned that they would check with the person they supported if they agreed to them providing the information required on their behalf (e.g. when answering questions on income and assets).

"If I HAD to respond to questions on income and assets, I would check with my dad if he was ok with me providing this information about his pension etc. It has to be done tactfully, not in a demanding way." – Unpaid carer

"I try to get on with everything myself. I try not to worry other people. [I try to be] Independent, that is the word I was looking for." - Person with care needs

7 Conclusions: risks and next steps

The findings from these cognitive testing interviews clearly highlight a number of risks if the survey is piloted or implemented in its current form.

7.1 Risks

There is a potential for distress because of the subject matter, which can be emotional and lead people to reflect on the extent of their care needs, how their needs are met, and how much it costs them and/or their family members. Also, the topic of some of the questions could worry participants: when discussing questions on income and assets, concerns around scams and fraud were frequently expressed. Participants wondered whether the survey was genuine, and why DHSC would want to collect data on income and assets. It is possible that clearer, more detailed information about the aims and objectives of the survey could alleviate concerns around whether the survey is genuine or not. Clearer communications about the topics covered in the survey could also reduce the risk of distress as people will know what questions to expect before starting to complete the survey (though this may lead to lower response rates). An additional mitigating measure would be to provide sources of support in a thank you/support leaflet at the end of the survey – as was done for the pilot.

Clearer and more detailed information about the aims and objectives of the survey is required to manage respondents' expectations regarding the outcome of their participation, and address their concerns about some of the questions. Despite a detailed information sheet, and an interviewer-administered consent process which involved verbally explaining the objectives of the survey, there was still misunderstanding about what DHSC wanted to achieve by collecting this information. There is a risk that some people could take part because they wrongly believe the survey is a care assessment, and that answering all the questions will help them to access care and support. There is a similar risk that some people won't take part because they assume that the data collected will be linked with other information held about them by the government or by their local authority, which could lead to their current or future entitlement to LA-funded care and/or benefits being removed or reduced or to being required to sell their home to pay for their care costs – a highly emotional topic. It is important that participation in surveys is done with fully informed consent and not because of a misapprehension about the outcome. Furthermore, if those who think they would benefit from taking part are more likely to take part and those who are anxious about the implications of revealing their financial status are more reluctant to take part, the achieved sample may be biased to those with lower levels of income and assets.

Regardless of the above, questions on assets and income were not considered acceptable, and very few participants said they would answer them – usually those on low income and/or with few or no assets. Others thought income and assets were 'private' matters and said they would select codes such as 'Prefer not to say' or 'Don't know'. Those who received benefits assumed government departments already held data about their financial situation. This means any data collected from the questions on income and assets are likely to be limited, and potentially biased.

An additional risk is the complexity of the topic areas and of the information that needs to be collected. There was uncertainty among participants regarding the meaning of important terms such as 'unpaid care', 'formal care and support services', and 'local-authority funded care' – which are crucial for the interpretation and understanding of the questions, and impact on the answer codes selected and the routing. Services such as 'personal assistant', 'reablement', and 'respite' were not always known or recognised, which could lead to under-reporting. While key terms could be explained as part of the

survey, this will add to the length and cognitive effort required, and this could put off some people from taking part.

Finally, survey responses will be affected by the cognitive effort required to provide the information requested, the need to recall information, and the lack of understanding regarding some of the terms used. This will affect the validity of survey responses about e.g. the number of hours of unpaid care received, and how much other family members are contributing toward care costs.

7.2   Next steps

In light of the above risks, we recommend against the piloting of the survey in its current form. Before a possible pilot, the following actions should be considered to help reduce some of the above risks:

- providing more detailed and clearer information about the aims and objectives of the survey;

- providing a Q&A about how the data will (and will not) be used;

- providing short definitions of key terms that were not well understood by participants, e.g. 'unpaid care,' 'formal care,' 'local-authority funded care';

- removing questions on income and assets which are not considered acceptable to the audience, and reviewing other questions in light of the feedback provided elsewhere in the report; and

- testing the survey invitation, Q&A, and revised questionnaire, to check they address the concerns raised by participants in this phase

Alternatively, DHSC may decide against doing a survey (if the key questions they require data from cannot be included) and instead further explore the feasibility of the remaining options that were considered during workstream 3 (structured appraisal of options for data collection on income and assets among people with care needs).

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